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Progress Notes: BUMC Parkinson's Disease Center

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Boston University



Progress Notes

A Report from the Parkinson's Disease Center at Boston University Medical Center

August 1992

FROM THE EDITOR

By the time this newsletter reaches you, it probably will be midsummer. I am happy to report we have had a very busy and successful year at the Information and Referral Center here at Boston University Medical Center. Last fall, the center organized what turned out to be a very successful Support Group Leaders Conference. Forty group leaders met at the Sheraton Tara in Braintree, Mass., for a day of sharing. Special guests included Kathryn Cullen, R.N., M.S., and John Curtain. Ms. Cullen is the center coordinator at Roger Williams Hospital in Providence, R.I. She did a wonderful job describing the many roles a Parkinson support group performs. Mr. Curtain, representing Sandoz Pharmaceuticals, did a presentation on PATH (a patient-education program for patients and families that was developed by Sandoz).

In June of this year, the center co-hosted a Parkinson Symposium with the Maine Chapter of the APDA. Two hundred individuals met on Saturday, June 12, in Bangor, Maine. Blaine and Glenna Atwood, with the help of many, organized the event. Speakers included Robert Feldman, M.D., George Wright, M.D., Kenneth Salmon, R.P.T., Linda Perry, R.N., M.Ed., and the Atwoods. It was a pleasure meeting those from the Northern New England area and from parts of Canada.

A local symposium is being planned for the latter part of fall this year. More information soon will be available. Enjoy the rest of the summer.

Sincerely,
Cathi Thomas, R.N., M.S.

Parkinson Day Program Update

by Linda Perry R.N., M.Ed.

Twice a week, the Parkinson's Day Program at Boston University Medical Center holds sessions aimed at assisting in the management of common problems experienced by individuals (including family members) affected by Parkinson's disease.

As a component of the outpatient treatment plan, the sessions were specifically designed to allow closer physician/nurse monitoring of the patients' medication response over a six-hour period, and provide education and support to patients, family members, and caregivers. We recently have added a second part of the session.

Part 1 provides an overview of Parkinson's disease, information on medication, supportive therapy and current treatment modalities.

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Research News from Boston University Medical Center

Several new research studies are under way at the Department of Neurology of Boston University Medical Center.

■ The first study will evaluate the efficacy of an experimental drug called Ropinirole in early Parkinson's disease. Individuals who participate must be on no medication for Parkinson's disease, or just selegiline (Eldepryl). Ropinirole is a dopamine agonist (see *Medical Update*, page 3).

■ The second study will look into the effects of a special diet on Parkinson's disease. The diet, which was developed at Interneuron Pharmaceuti-

cals, will be utilized on patients with "wearing off" and/or dyskinesias.

■ The third study will evaluate balance problems associated with Parkinson's disease. The study will take place at Braintree Hospital, and the principal investigator is Jules Friedman, M.D., a neurologist with expertise in this area. Robert Feldman, M.D., and Marie Saint-Hilaire, M.D., will assist with this project.

■ Finally, data collection is almost complete on the nursing study "Managing the Trajectory of Care." We expect to enroll approximately 25 more pa-

tients. This study is being conducted by Ellen Mahoney, D.N.S., a faculty member at Boston College School of Nursing, Linda Perry, and Cathi Thomas.

If you would like more information on these studies, please call 617-266-1565.



Day Program

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Part 2 focuses on problem solving, coping mechanisms and stress management. Small group discussion centers around the impact of the diagnosis and changes that occur as the disease progresses. The discussion also focuses on the use of appropriate coping strategies to help the patient and family deal effectively with their problems. Stress management techniques are introduced and include imagery tapes that were developed by Dr. Peter Mosbach, BUMC psychologist, concepts from Dr. David Burn's *Feeling Good Handbook*, and Dr. Arlin Brown's relaxation response audiotapes.

The Parkinson's Day Program is directed by Dr. Marie Saint-Hilaire, who specializes in the treatment of movement disorders, and is coordinated by Linda Perry, R.N., M.Ed. Special consultation with specific therapies can be arranged with advanced notice.

For additional information, please call 617-266-1565.

Support Group News

During the past year, three new support groups have been established. The first group, which just celebrated a one-year anniversary, is the "Young Parkinson Support Group." The group has grown tremendously and has had a positive impact on those affected by Parkinson's disease. Ken Bernstein organized the group and currently serves as the president of the newly formed YPSG/APDA chapter. Meetings are held monthly at Newton-Wellesley Hospital. For further information, please call Ken at 617-527-2803.

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Walkathoners listen as Ken Bernstein reads a proclamation from Governor William Weld about the seriousness of Parkinson's disease.

Mass. Chapter News

by Jeanne McCarthy

Once again, we have completed a successful walkathon to raise money for Parkinson's disease. On Saturday, May 16, many old faces and lots of new ones arrived at the Cleveland Circle Reservoir in Brookline, Mass., to pledge their support for Parkinson's research. The day started with clouds and rain showers, but within an hour, the sun was shining. We collected \$4,737 on site, with many other pledges to be sent to the national office.

Support groups really were the key to this year's success. The walk would not have been possible without the efforts of many of the groups, and I would like to especially thank the Norwood Parkinson Support group, the Young Parkinson Support Group, the Southwood Parkinson Support Group, the Newton Wellesley Support Group and the South Shore Support Group. Many people were unable to walk, but were able to volunteer in other ways. Ken Bernstein, this year's recipient of the Massachusetts Chapter award, read a proclamation from Governor William Weld recognizing the seriousness of Parkinson's disease.

On the same day, the Cape Cod Support Group also held a very successful walk, organized by Helen Perreult. Group members, their families and friends gathered at the Brewster Candy Store for their five-mile journey.

Special thanks go to our Walkathon supporters: Boston University Medical Center/The University Hospital; Coolidge Corner Clubhouse; The Hood Company; International Ice Cream Distributors; John Hancock Financial Services; Trophies and Awards; The Bishop Family; John Berardi; Ken Bernstein; Nick's Comedy; Nunsense; Dr. and Mrs. Robert Feldman; Sandoz Pharmaceuticals; Stop and Shop Inc.; and Dick Goldstein.

MEDICAL UPDATE:

The Use of Dopamine Agonists in Parkinson's Disease

by Marie Saint-Hilaire, M.D.

The signs and symptoms of Parkinson's disease are primarily caused by a decrease of Dopamine in the brain. Thus, the basis of treatment is to replenish the brain with dopamine. This is best accomplished by administering levodopa which, when entering the brain, is transformed into dopamine. Levodopa (usually given in the form of Sinemet), is the most effective antiparkinson medication. However, long-term treatment with Sinemet usually is associated with such significant complications as abnormal involuntary movements and fluctuations in mobility (on-off). Other medications have been developed to prevent or alleviate these complications. Dopamine agonists are important therapeutic options to

deal with complications of levodopa therapy.

Dopamine agonists bypass the degenerating neurons of the substantia nigra and act directly on the dopamine receptors in the brain. They do not need to be converted into dopamine as levodopa does, and they are more stable and longer-acting than levodopa. Dopamine agonists were first used for treating advanced Parkinson's disease; now they are also used early in the course of the disease with or without treatment with levodopa (Sinemet).

In the United States two dopamine agonists, Bromocriptine (Parlodel) and Pergolide (Permax) have been approved by the FDA and are widely used. Bromocriptine, which has been used since the 1970's, is helpful when added to levodopa in patients with wearing-off and dyskinesia (involuntary movements). It decreases fluctuations in mobility and frequently allows the patient to take less levodopa. Studies have demonstrated that the early introduction of bromocriptine can lessen the long-term complications of levodopa therapy. It is now used early in treatment when patients are still on a low dose of levodopa (Sinemet). Pa-

tients who use a combination of low-dose levodopa and bromocriptine develop less dyskinesias and motor fluctuations than do patients on high doses of levodopa alone.

Bromocriptine also has been shown to be an effective medication in untreated patients, who also are not taking levodopa. Eventually, however, most patients will need to start levodopa treatment as the symptoms worsen.

Bromocriptine is available in 2.5mg tablets and 5mg capsules. Daily doses vary from patient to patient but can range from 1.25mg per day to as high as 70mg. per day (although in rare instances). Side effects include low blood pressure, confusion, hallucinations and nausea. Patients usually start with a very low dose to avoid these side effects.

More recently, pergolide (Permax) has been approved. Its indication are the same as bromocriptine. Pergolide is more potent than bromocriptine because it stimulates both D1 and D2 receptors. The side effects of pergolide include nausea, confusion, hallucinations and decrease in blood pressure. Some studies have shown that patients who do not tolerate bromocriptine may better tolerate pergolide and visa-versa. Pergolide is most often used in patients who did not tolerate bromocriptine or in patients with severe fluctuations who do not respond to high doses of bromocriptine. Pergolide is available in 0.05mg, 0.25mg and 1mg tablets. The standard dosage is 1mg, three times a day, but some patients need lower or higher doses. As with bromocriptine, the dose is slowly increased.

Other dopamine agonists are being used and studied mainly in Europe or on an experimental basis in the United States. They include lisuride and apomorphine. Lisuride can be given as subcutaneous infusion (needle or catheter under the skin) through a pump, similar to insulin infusions for diabetics. It does significantly improve fluctuations but can cause severe confusion.

Support Group News

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The second group, under the direction of Sharon Feccia, meets monthly (third Wednesday of the month) at the Milford-Whitinsville Hospital. Thanks to Sharon's efforts, more than 70 people attended the initial meeting. Dr. William Tosches, a neurologist and chief of staff at the hospital, gave a comprehensive overview of Parkinson's disease. Dr. Tosches will be available as a medical consultant for the group. For information, please call 508-473-1190. The third group meets in Martha's Vineyard at the Council of Aging. The group was organized by Jane McGrath and already has attracted eleven members. For further information please call 508-696-4205. The center wishes much success to these groups.

Leadership position available. Joan and Frank Engstrom have stepped down as leaders of the Southwood Parkinson Support Group, as they have relocated out West. Mrs. Marie Melchen will temporarily organize the meetings, but is looking for an individual or individuals to assume leadership. If you are interested, please call 617-638-8466 as soon as possible.

**Change of Contact Person,
Cape Cod Parkinson Support Group**
Contact: Frederick Lawton
76 Wampanoag Trail
Dennis, MA 02638
508-385-2565

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Dopamine Agonists

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Apomorphine was the earliest dopamine agonist used in Parkinson's disease, but was abandoned because of such side effects as nausea and hypotension, and also because it only is more effective when given intravenously. It now is used as a subcutaneous injection that patients can administer themselves for rapid "turn-on"

during a disabling period. Generally, patients use it when in important situations and not on a continuous basis. A medication called domperidone usually is used with apomorphine to decrease side effects.

A new dopamine agonist, Ropinirole, not yet approved by the FDA, is

being studied in many centers around the country. This medication will be studied at Boston University Medical Center starting this summer (see new research).

Progress Notes is intended solely to provide you with information that you can discuss with your physician. You should not make any changes in your treatment without first discussing them with your physician.

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